

The Texas Birth Defects MONITOR

An Annual Data and Research Update



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The 25th Anniversary of the Texas Birth Defects Registry: Looking Back at the Beginning of Data Gathering to Prevent Birth Defects

Congratulations, you're pregnant! Reality starts to diminish the early glow of pregnancy as your doctor recommends a dizzying list of prenatal screening tests. With trepidation, you agree to the tests.

But what happens if those test show your baby has a birth defect? Parents faced with the worst news of their life ask, "Why my child?" Twenty-five years ago, before there was a Birth Defects Registry, there were no answers. Doctors could give the parents information about how to deal with a disability or recommend palliative care, but there were few answers. And there was little to prevent this from happening to other families in the community. Today, the Texas Birth Defects Registry gathers data to help answer "why." Researchers use that data to find causes and prevent birth defects.

Palliative care is specialized medical care focused on providing relief from symptoms and stress of a serious illness or birth defect. The goal is to improve quality of life for both the patient and the family.

Carmen Rocco, MD, remembers the cluster of babies born with anencephaly in 1990-1991. Rocco was a physician at Brownsville Community Health Center. "I was caught in the middle of one of the scariest adverse health outcomes in my community, Dr. Rocco said. "Before the cluster started its mysterious downward trend, we had seen over 30 cases of anencephaly and spina bifida in an 18-month period. Scientific communities that follow these defects, would describe it as one of the largest clusters in medical history."

Sign up for email updates from the Texas Birth Defects Epidemiology and Surveillance Branch at <https://www.dshs.texas.gov/birthdefects/>.

There was no Texas Birth Defects Registry. People called the Texas Department of Health (now Texas Department of State Health Services, DSHS). Dennis Perrotta, PhD, state Epidemiologist, got a call from a nurse. “How many cases of these birth defects should we expect?” she asked.

Dr. Perrotta and DSHS staff spent years trying to answer that question and figure out if there was a higher incidence of birth defects in the Rio Grande Valley. “Families had questions and were calling us on a regular basis about birth defects in their neighborhood,” said

Anencephaly and spina bifida are severe birth defects where a hollow structure (neural tube), from which the brain and spinal cord form, does not fuse in early pregnancy. In Anencephaly, this results in the baby developing without cerebral hemispheres, including the neocortex, which is responsible for cognition. In spina bifida, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves.

Perrotta. Gathering data from birth certificates was slow, hard work. “At that time, we had no organized way to take a look at birth certificates, death certificates, doctors’ offices – no way to get the information quickly to see if rates are normal or higher than normal,” said Perrotta. Birth and death certificates weren’t always accurately filled out to indicate a birth defect.

Meanwhile, the Brownsville, Texas, community worked to get funding for their own study. They had to comb many inconsistent records and other hospital information. The information was sometimes unreliable.

DSHS finally had enough data to confirm a high rate of anencephaly, spina bifida and other birth defects in the area. With the help of a grant from The Centers for Disease Control and Prevention (CDC), they worked to find out why.

Active Surveillance is used when there is indication that something unusual is happening. The health department actively looks for cases by examining medical records and calling health care providers or laboratories and requesting information about the birth defect or disease. While this method costs more and is labor intensive, it tends to provide a more complete estimate of frequency.

But the information gathering process had been long and difficult. DSHS needed a way to gather information reliably, so that they could respond quickly when birth defects clusters were found. DSHS needed an active surveillance system. Authority and funding to make that possible would require support from the Texas Legislature.

The DSHS presented Senate Bill 89 to the Texas Legislature in 1993. People who knew the devastating impact of birth defects advocated for the Bill: Anne Andis, mother of a baby girl with anencephaly; Kevin Brady, state representative; Melanie Lockhart, Executive Director of the Central Texas Chapter of the March of Dimes; and many others. Heightened media interest helped drive the Bill forward.

In May 1993, the Birth Defects Act passed the Legislature. In June, Governor Ann Richards signed the Birth Defects Act into law. Both Andis and Dr. Perrotta still treasure the pens used to sign it. In September, the Birth Defects Act went into effect. Division offices opened in March 1994 and data collection began in December. Since 1994, the Birth Defects registry has collected 360,000 cases.

Dr. Perrotta says the Texas Birth Defects Registry is “what makes me proudest from my 29 years of public health experience. Our Registry is one of the finest birth defect registries in the country. In some cases, it’s known in international circles.”

“I use the Registry, and I am so incredulous of the amount of information that is in the Registry,” said Rocco “It is so reliable, so accessible and so important in monitoring birth defects in any community.”

Gathering all Texas birth defects data into one place is an important tool. It lets researchers investigate the “why” of birth defects. Finding a pattern leads to prevention that saves babies' lives.

“Reporting is essential and accuracy is as important,” said Paula Gomez, Director of the Brownsville Community Health Center. “It can lead to interventions that may prevent things in the future.”

“Thanks to birth defects surveillance and research, we now know that taking folic acid before and during early pregnancy can help prevent neural tube defects,” Lockhart said.

For 25 years, the information gathered in the Texas Birth Defects Registry has contributed to research, improved health and saved lives. “The Registry makes what happened to those babies count,” Andis said.



Governor Ann Richards signed the Birth Defects Act into law in June of 1993.

Read more about Anne Andis’ story in *The 25th Anniversary of the Texas Birth Defects Registry: Making Birth Defects Count, a Mother’s Story*, on page 8.

Recent Data from the Pregnancy Risk Assessment Monitoring System

The Pregnancy Risk Assessment Monitoring System (PRAMS) survey, designed by the Centers for Disease Control and Prevention (CDC), samples women who have recently given birth and asks them questions on important health topics, including access to prenatal care, smoking and smoke exposure, alcohol use, obstetric history, economic status, medication use, and more.

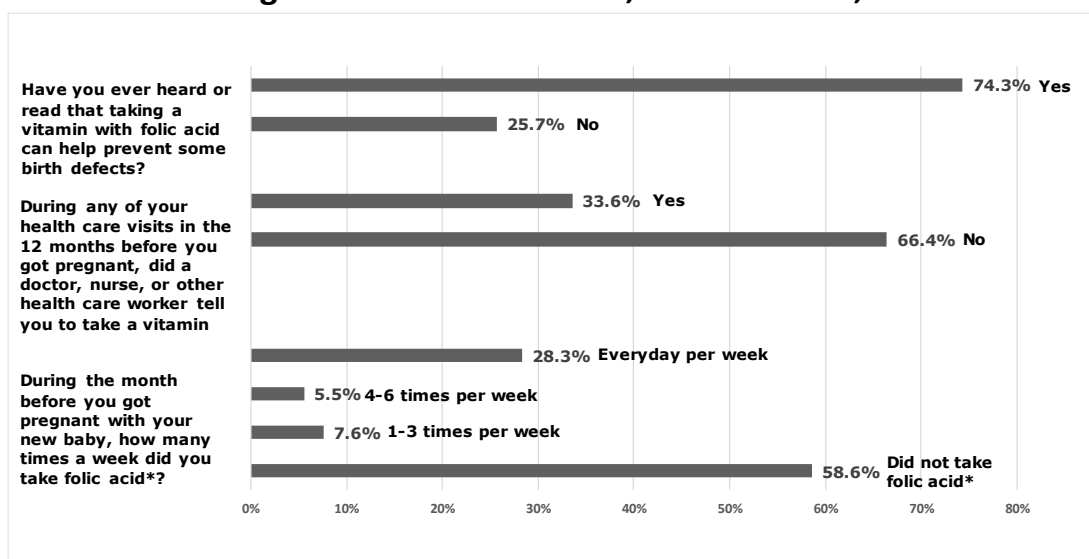
Texas has participated in the PRAMS survey since 2002. The Maternal and Child Health Epidemiology Unit at the Texas Department of State Health Services recently published PRAMS data for 2016. One important component of the PRAMS survey is questions regarding folic acid use and knowledge about folic acid. Folic acid is known to reduce the risk of neural tube defects (NTDs), a group of birth defects of the brain and spinal cord such as spina bifida and anencephaly. It is challenging to consume enough bioavailable folic acid (i.e. food folate) through diet alone. Therefore, the recommendation is for use of the supplemental form of folic acid (400 micrograms), found in essentially all multivitamins. When taken properly

(i.e. daily) the risk of NTDs is reduced by more than 70 percent. The chart below shows the results of several questions surrounding folic acid from the PRAMS survey. In 2016, 1,849 respondents completed the survey representing 390,637 women who were residents of Texas and gave birth to a live infant.

The majority of women reported that they knew that taking a vitamin with folic acid can help prevent birth defects (74.3%). However, more than half (58.6%) of the women did not take a multivitamin, prenatal vitamin, or folic acid vitamin in the month prior to pregnancy. Of the women who had a health care visit in the 12 months before becoming pregnant, two-thirds (66.4%) reported that they were not told to take folic acid by a healthcare professional.

Only 28.3% of women of childbearing age took a daily folic acid-containing supplement in the month prior to pregnancy, despite the recommendation that all women of child bearing age follow this practice.

Knowledge and Use of Folic Acid, Texas PRAMS, 2016



*a multivitamin, a prenatal vitamin, or a folic acid vitamin

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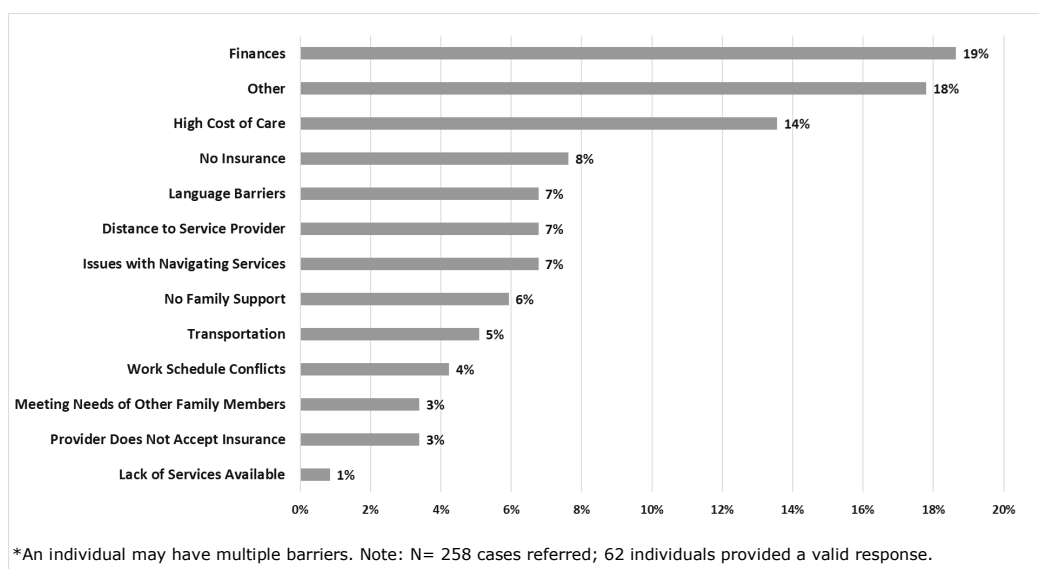
Update on Registry-based Family Outreach Activities

Birth Defect Referrals (Case Management)

Birth Defects Epidemiology and Surveillance (BDES) has collaborated with the Division for Regional & Local Health Operations (RLHO) in contacting families with an infant recently born with selected anomalies. This pilot involves continued work with RLHO in identifying services these families were receiving, new services they were referred to, and barriers to services.

This project will help us better understand challenges encountered by families with infants affected with birth defects, and can potentially improve efforts in outreach and services that are provided. The chart below describe reported barriers to receiving services among infants identified from the Texas Birth Defects Registry with spina bifida, encephalocele, and orofacial clefts. Additional birth defects are being added or considered for case management, most recently Down syndrome.

Barriers* to Receiving Services for the Texas BDES Case Referral Initiative, July 2018



Maternal Interviews

BDES identifies recent deliveries affected by a neural tube defect (NTD: anencephaly, spina bifida, encephalocele) and mails information packets to families, regarding increased risk for NTDs in future pregnancies. This project aims to reduce the risk of another NTD-affected pregnancy through the recommendation of consulting a health care provider regarding daily use of higher dose folic acid (described in the 2017 issue of the Texas Birth Defects Monitor).

In 2018, BDES contracted with the Public Policy Research Institute (PPRI) at Texas A&M University to conduct a survey to evaluate the effectiveness of the mail-outs for the Branch's NTD Recurrence Prevention Project. This assessment provides information on whether these women are receiving the mail-outs and if they understand and follow the recommendations surrounding folic acid. An additional component includes basic questions about the child's health care. BDES staff and partners will continue the survey in 2019. An additional survey will be implemented in 2019 focused on the health care of children with Critical Congenital Heart Defects (CCHDs).

These family outreach activities were supported in part by the Centers for Disease Control and Prevention (CDC) grant CDC-RFA-DD16-1601, "Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization," and Title V, Children with Special Health Care Needs, and Texas Parent-to-Parent Family Support Group.

Maternal Report of Fever from Cold or Flu during Early Pregnancy and the Risk for Noncardiac Birth Defects, National Birth Defects Prevention Study, 1997-2011

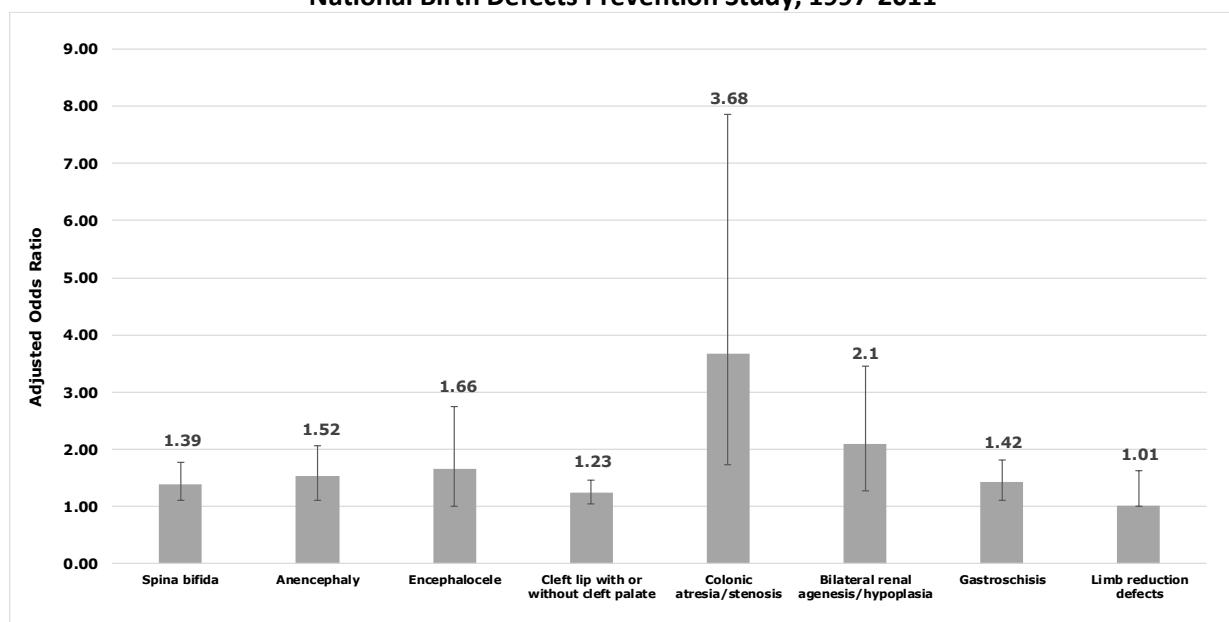
Previous research has shown an association between maternal fever during early pregnancy and some types of birth defects. This case-control study used data from the National Birth Defects Prevention study, a multistate case-control study of major birth defects, to assess the association between maternal fever during early pregnancy and 30 non-cardiac birth defects.

A total of 17,162 mothers of cases and 10,127 mothers of controls who completed a telephone interview were included in this study. Multivariable logistic regression was used to assess the association between maternal self-report of cold or flu with fever and cold or flu without fever during early pregnancy and 30 categories of non-cardiac birth defects.

Main findings from this research: Maternal report of cold or flu with fever was significantly associated with 8 birth defects, as shown in the chart below. Maternal report of a cold or flu without fever, and maternal fever reported in later pregnancy, were not associated with any birth defects studied. Adjusted odds ratios that were associated with maternal reports of cold or flu with a fever of ≥ 101 degrees Fahrenheit (F) were not substantially different from the adjusted odds ratios associated with maternal report of cold or flu with a fever <101 degrees F.

This study found further evidence that maternal fever during early pregnancy is associated with an increased risk for certain birth defects. This increase was limited to mothers who reported having a fever, suggesting that the fever contributes to the increase in risk of birth defects and not the illnesses that can accompany the fever. Nonetheless, having a fever can also be an indicator of having other severe illnesses or infections.

**Noncardiac Birth Defects Significantly Associated with Periconceptional Fever,
National Birth Defects Prevention Study, 1997-2011**



Waller DK, Hashmi SS, Hoyt AT, Duong HT, Tinker SC, Galloway MS, Olney RS, Finnell RH, Hecht JT, Canfield MA, the National Birth Defects Prevention Study. Maternal Report of Fever from Cold or Flu during Early Pregnancy and the Risk for Noncardiac Birth Defects, National Birth Defects Prevention Study, 1997-2011. *Birth Defects Research*. 2017;00:1-10.

Best for You. Best for Baby. 5 Tips for Preventing Birth Defects.

January is National Birth Defects Prevention Month

This year's theme is **"Best for You. Best for Baby."** Not all birth defects can be prevented. But you can increase your chances of having a healthy baby by doing what you can to be your healthiest self both before and during pregnancy.

Tip 1: Be sure to take 400 micrograms (mcg) of folic acid every day. Folic acid is very important because it can help prevent some major birth defects of the baby's brain and spine. Our bodies use this B vitamin to make new cells.

Tip 2 Book a visit with your healthcare provider before stopping or starting any medicine. Many women need to take medicine to stay healthy, and there are often benefits to continuing your treatment throughout your pregnancy. If you are trying to have a baby or are just thinking about it, now is a great time to start getting ready for pregnancy by talking with your doctor about medications you may be taking.

Tip 3: Become up-to-date with all vaccines, including the flu shot. Vaccines help protect you and your baby. Some vaccinations, such as the flu (influenza) vaccine and the Tdap vaccine (adult tetanus, diphtheria, and acellular pertussis vaccine), are specifically recommended during each pregnancy.

Tip 4: Before you get pregnant, try to reach a healthy weight. Obesity increases the risk for several serious birth defects and other pregnancy complications. If you are underweight, overweight, or obese, talk with your healthcare provider about ways to reach and maintain a healthy weight before you get pregnant. Eating healthy foods and being physically active are great ways to prepare for pregnancy.

Tip 5: Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs.

January 6-12 is Folic Acid Awareness Week

Folate is found naturally in certain fruits, vegetables, and nuts. Folic acid is found in fortified foods (called "enriched foods"), such as breads, pastas, and cereals. In addition to eating foods with folate from a varied diet (including foods like spinach and avocado), you can:

- Take a vitamin that has folic acid in it every day.
 - Vitamins can be found at most local pharmacies and grocery stores. Check the label on the bottle to be sure it contains 100% of the daily value (DV) of folic acid, which is 400 mcg.
 - Most vitamins sold in the United States have the recommended amount of folic acid women need each day.
- Eat fortified foods.
 - You can find folic acid in some breads, pasta, breakfast cereals, and corn masa flour.
 - Be sure to check the nutrition facts label and look for one that has "100%" next to folate.

Source acknowledgement: National Birth Defects Prevention Network Education and Outreach Committee.

The 25th Anniversary of the Texas Birth Defects Registry: Making Birth Defects Count, a Mother's Story

Anne Andis is a mother who knows firsthand the devastation of hearing, "Your baby has a birth defect." In 1992, Andis was pregnant with a daughter. After her 20-week ultrasound, her doctor diagnosed a neural tube defect called anencephaly.

"Why my child?" Andis asked, grieving even as she carried her daughter to term. And yet, she will never regret the five wonderful days she spent with her baby girl. "She was beautiful," Andis said. She wanted that beauty to count for something. "Grief can motivate you."

Twenty-five years ago, before there was a Texas Birth Defects Registry, there were no answers. There was nothing doctors could do to extend the short life of a baby with anencephaly. There was nothing anyone could do to change or reverse the fatal birth defect.

Andis' neighbors in The Woodlands, near Houston, Texas, heard about her daughter. And they too had stories to tell. They called to tell Andis about other babies in the area born with neural tube birth defects. Andis wrote each of these stories on an index card. The stack of cards grew to three inches thick. "I was grieving and wanted my daughter's life to count," Andis said. "I couldn't walk away."

Andis called the CDC to ask why they were not doing anything about birth defects in The Woodlands. She had been reading anything she could find on birth defects, so Andis knew about the cluster of anencephaly and the work to track birth defects in Brownsville, Texas. The CDC told Andis to call the Texas Department of Health (now Texas Department of State Health Services, DSHS). But the health department didn't yet have a way to track birth defects.

While state officials were working with state legislators in the Lower Rio Grande Valley, Andis turned to her state representative, Kevin Brady. "We need to investigate," Andis said. "There are at least 30 other people in The Woodlands who have lost children to birth defects." She also pointed to the birth defects in Brownsville, Texas. Brady agreed to help. Andis is still grateful. "What is important is how hard Kevin worked," she said.

The hard work had only begun. Many people researched information needed to present their case to the Texas Legislature. DSHS staff wrote a Bill to ask the Texas Legislature for authority and funding to make a

Anencephaly is a severe birth defect where a hollow structure (neural tube) from which the brain and spinal cord form, does not fuse in early pregnancy. This results in the baby developing without cerebral hemispheres, including the neocortex, which is responsible for cognition.

Neural tube defects are birth defects where a hollow structure (neural tube), from which the brain and spinal cord form, does not fuse early in pregnancy. The two most common neural tube defects are spina bifida and anencephaly. In Anencephaly, this results in the baby developing without cerebral hemispheres, including the neocortex, which is responsible for cognition. In spina bifida, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves.

(Continued on page 9)

(The 25th Anniversary of the Texas Birth Defects Registry: Making Birth Defects Count, a Mother's Story, continued from page 8)

Texas Birth Defects Registry possible. Andis advocated for the Bill by telling her story. She talked about her daughter and shared her index cards. "It was a team effort," Andis said. "Everyone was on the same page."

In May 1993, the Birth Defects Act passed the Legislature. In June, Governor Ann Richards signed the Birth Defects Act into law. Andis still has a pen used to sign it. Even more, she treasures the memory of Governor Richards' kindness. Andis said, "She gave me a big hug and said, 'Anything we can do to protect our babies!'"

The Birth Defects Act went into effect in September 1993. Division offices opened in March 1994 and data collection began the following December. Today, the Texas Birth Defects Registry gathers data to help answer "why." Researchers use that data to find causes and prevent birth defects. "The Registry makes what happened to those babies count," Andis said.



Anne Andis advocating for the Texas Birth Defects Act

The 25th anniversary of the Texas Birth Defects Registry was observed at the 2018 Biennial BDES Technical Training for all staff. The commemoration included a panel of individuals involved the legislative process of creating the Registry. Panelists included Anne Andis, a resident of the Woodlands (see story above), former State Epidemiologist Dr. Dennis Perrotta, former Brownsville Community Health Center physician Dr. Carmen Rocco, and Melanie Lockhart, who helped spearhead the March of Dimes advocacy efforts in Texas in the 1990s.



The International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and participating organizations are raising awareness of birth defects with World Birth Defects Day, held on March 3. The

ICBDSR hopes to increase global awareness of birth defects and promote expansion of birth defects surveillance, prevention, research, and care with this event.

To learn more, visit <http://www.icbdsr.org/>.

Understanding how the concentration of neighborhood advantage and disadvantage affects spina bifida risk among births to non-Hispanic white and Hispanic women, Texas, 1999–2014

Using the index of concentration at extremes (ICE), the authors examined risk factors for spina bifida in Texas. This study introduces two novel measures of neighborhood characteristics (language and nativity) as well as three existing ICE measures (race/ethnicity, income, and education), to examine whether spina bifida risk is associated with neighborhood advantage or disadvantage.

Previous research has found an association between spina bifida and lower socioeconomic status (SES) at an individual and neighborhood level. One element of neighborhood disadvantage is the degree two or more groups live separately. This concentration of advantage or disadvantage at the neighborhood level influences health, possibly due to differing economic, physical, and social neighborhood environments which influence health behaviors. The Index of Concentration at the Extremes (ICE) is a useful way to explore the degree to which residents in an area are concentrated into groups at the extremes of disadvantage and advantage. In this analysis, the authors used multivariable mixed-model Poisson regression to estimate prevalence and prevalence ratios for each ICE measure among singleton live births in Texas from 1999–2014. Analyses were stratified by maternal race/ethnicity (Hispanics and non-Hispanic whites).

The authors concluded that ICE risk patterns were different for non-Hispanic whites and Hispanics. They found that among non-Hispanic white women, those in the most disadvantaged versus the most advantaged census tract quintile had adjusted relative risk between 1.6 and 8.5 for having a baby affected by spina bifida (i.e. 60% to 8.5-fold higher risk).

Significant associations were seen in the expected direction for ICE measures. Decreasing Q1:Q5 gradients in risk were observed for all ICE

measures variables, from the lowest quintile to the highest:

- language [adjusted prevalence ratio (adj. PR) = 4.04 (95% CI = 2.17–7.11)],
- income [adj. PR = 4.41 (95% CI = 2.67–7.07)],
- ethnicity [adj. PR = 4.05 (95% CI = 2.10–7.27)],
- education [adj. PR = 8.53 (95% CI = 2.10–7.27)].

In contrast, Hispanic women in the most disadvantaged versus advantaged census tract quintile for four ICE measures had a 33% to 87% lower risk of having an affected pregnancy. Increasing Q1:Q5 gradients of risk were observed for 4 of 5 ICE measures:

- language [adj. PR = 0.13 (95% CI = 0.09–0.21)],
- nativity (foreign vs. U.S.-born) [adj. PR = 0.27 (95% CI = 0.18–0.41)],
- race/ethnicity [adj. PR = 0.16 (95% CI = 0.10–0.26)], and
- education [adj. PR = 0.67 (95% CI = 0.47–0.97)].

Neighborhood disadvantage and the concentrations of disadvantage and advantage is an important dimension of socioeconomic status and a factor that should be accounted for in studies of birth defects. This study concluded ICE risk patterns for spina bifida were different for non-Hispanic whites and Hispanics. Future work will assess the method for other birth defects, determine if estimates differ based on changing quintile cut points, and analyzing the ICE measures as continuous variables in the models.

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Recent Publications from BDES Branch Staff and Collaborators

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2019 Calendar

The Monitor is published annually by the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services.

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Please visit the BDES website for updated information and to sign up for Branch updates: www.dshs.texas.gov/birthdefects/.

Requests for copies or back issues may be made to: birthdefects@dshs.texas.gov.

- January: National Birth Defects Prevention Month
- January 6-12: National Folic Acid Awareness Week
- February: American Heart Month
- February: International Prenatal Infection Prevention Month
- February 14: Congenital Heart Defect Awareness Day
- Spring 2019: March of Dimes March for Babies (check with MOD for specific dates and locations)
- March: National Nutrition Month
- March: National Developmental Disabilities Awareness Month
- March 9-12: Association of Maternal and Child Health Programs (AMCHP) Annual Conference, San Antonio, Texas
- March 17-20: National Family Planning & Reproductive Health 2019 National Conference
- April: Alcohol Awareness Month
- April: National Autism Awareness Month
- April: National Minority Health Month
- April 1-7: National Public Health Week, American Public Health
- May 14-20: National Women's Health Week
- June 17-18: 32nd Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research, Minneapolis, MN
- June 22-26: 59th Annual Meeting of the Teratology Society, San Diego, CA
- July: National Cleft and Craniofacial Awareness & Prevention Month
- July 30: Gastroschisis Awareness Day
- September: Childhood Cancer Awareness Month
- September: Newborn Screening Awareness Month
- September: National Infant Mortality Awareness Month
- September 8-11: 46th International Clearinghouse for Birth Defects Surveillance and Research Annual Meeting, Bratislava, Slovak Republic
- October: National Spina Bifida Awareness Month
- October: National Down Syndrome Awareness Month
- November: Prematurity Awareness Month (March of Dimes)
- November 2-6: American Public Health Association Annual Meeting, Philadelphia, PA

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